Testimony for Public Hearing Human Services Committee February 23, 2016

Julie Castillo 43 Rogers Road Hampton, CT 06247 Juliecastillo0908@gmail.com

H.B. No. 5249: An Act Establishing The Connecticut Traumatic Brain Injury Advisory Board

Senator Moore, Representative Abercrombie, Senator Markley, Representative Wood and members of the Human Services Committee:

Thank you for introducing this important legislation and for giving me the opportunity to explain why passing this bill is a critical step toward improving the system of services for those recovering from traumatic brain injury in Connecticut.

My name is Julie Castillo, and I am the current Chair of the Connecticut Traumatic Brain Injury Advisory Board. My sister, Alison, is recovering from a severe traumatic brain injury (TBI). In the six years since Allie's injury, my family and I have experienced incredible hardships, as well as many moments of hope and joy.

Our lives have revolved around doing everything in our power to help Allie get better, and it has not been an easy road. I could go into great detail about the difficulty we have faced in ensuring she receives the care she needs, but I will just say that no one should be denied the chance to reach their full potential, at any point in their lives. No one should be mistreated, brushed aside, or forced to live out of their home state just to receive basic rehab services. No family should ever have to fight so hard for their loved ones care while their loved ones fight for their lives.

While exploring every avenue to try and find her proper treatment, I came across the Connecticut TBI Advisory Board page on the Dept. of Social Services website. I set up a meeting with a few members of the Board in hopes of finding answers, but was saddened to learn that my experience was far from unique. This group of extremely dedicated people had been working toward the improvement of the system of care in CT for many years, and for many complex reasons, was having trouble getting traction. I decided to become a member. A couple of years later I was voted in as Secretary, and I am now serving my third year as Chairperson.

The mission of the Connecticut TBI Advisory Board is to promote the creation, collaboration and coordination of person-driven, accessible, supports, programs and services for persons with traumatic brain injury, their families and significant others.

While there are numerous generic services and programs for persons with traumatic brain injury in Connecticut, these services and programs are located within diverse agencies and organizations. These parallel systems lack a central point for coordination, comprehensive planning, evaluation, and monitoring. The TBI Advisory Board seeks to guide and advise the State in developing a comprehensive system of services by becoming the interdepartmental, interagency, and

interdisciplinary planning and advisory body for the departments and agencies of the State that are responsible for programs and services for persons with traumatic brain injury.

In reviewing TBI-related boards and councils across the nation, we found that 22 states have organizations that were established through state statute, seven were established by their designated state agency, and four states established their councils through executive order. It is clear that many other states are vastly ahead of ours in meeting the complex needs of those recovering from brain injury.

There has never been a better time for our state to take a stand on this critical issue. Both nationally and here in CT, there is a growing trend toward positive change related to concussions, Medicaid waivers, and significant discussion related to the large numbers of both identified and underidentified persons with brain injury, such as Veterans injured in the Iraq and Afghanistan wars.

The time to act is now. Every day that passes is another day that countless CT residents with TBI live without the services and resources necessary for optimal recovery, like my sister did for so many years. The lack of a coordinated, continuous system of recovery results in longer institutionalization and lengthened dependency on state funds. Early, seamless, and quality interventions will save the state money, and more importantly, will help more people return to the quality of life they deserve.

Please support this legislation to allow the Connecticut TBI Advisory Board to help improve the lives of those recovering from TBI. Brain injury can happen to anyone, anywhere, at any time. Help us ensure that we live in a state where if this happens to one of us, we will not face so many barriers to a full recovery.

Thank you for your time and for your support of H.B. 5249.

Sincerely,

Julie Castillo